



The Research Connection

The Psychosocial & Nursing Advisory Board to
the New Jersey Commission on Cancer Research

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The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the Commission of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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Are Hospice and Palliative Care Synonyms?

by
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For many professionals and the public, the words hospice and palliative care (when they are understood at all) are considered synonyms. A recommendation for palliative care is assumed to be a signal that further attempts at cure are futile. This is unfortunate because it is now clear that the concept of palliative care has adaptations and benefits for all patients experiencing the burden of serious or chronic illnesses and should be integrated as early as the initial diagnosis.

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Hospice

The hospice concept emerged in the United States in the early 1970's in response to a number of compelling motivating factors. These included the work of Elizabeth Kubler Ross who identified the abandonment of dying and suffering patients in hospital settings; the developing British model of care for this population by Dame Cicely Saunders; and the emergence of a grassroots movement to change the dynamics and paradigm of how care was delivered to the family and patients at the end of life. A number of "pioneers" began to envision a concept of care that transcended the medical model and encompassed the patient/family in decision making, in a setting that incorporated the talents and skills of a broad based coalition of caregivers.

The movement suffered all of the typical obstacles that innovative and creative approaches experience; initial rejection from the traditional healthcare community; fear on the part of patients that this movement would hasten their dying or force their acceptance of the futility of treatment; lack of funding and reimbursement; and a dearth of resources to serve these new imperatives. The initiation of federal funding for hospice through Medicare proved to be a mixed blessing; services became officially sanctioned and reimbursed but were "governmentalized" and thus subject to rigid definitions and exclusions. Current reimbursement for hospice now requires specific conditions: a six-month or shorter prognosis, a primary care provider available (if at home), agreement to forgo curative care and responsiveness to the medical director (varies by type of hospice). Nonetheless, the revolution in the delivery of end of life care was a tremendous milestone and changed the face of healthcare delivery.

Palliative Care

The mission of hospice care is coordinated care based on a biopsychosocial model rather than a physician/disease model that incorporates the

patient and family in a comprehensive approach to the relief of suffering and attention to quality of life. The developing science around the formerly grass roots movement identified a newly discovered, but long-standing, definition of care: palliative care. This word and concept of care were initially reserved for end-of-life consideration. However, it is now clear that good health care is a continuum and the value of this approach is appropriate for a far broader audience.ⁱ The World Health Organization defines Palliative Care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness; through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual."ⁱⁱ While the definition goes on to include relief from pain and other distressing symptom's, affirms life and regards dying as a normal process that would be neither hastened or postponed, it also talks about "*enhancing quality of life, and the opportunity to positively influence the course of illness which is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life*; such as chemotherapy or radiation therapy. They also urge investigations in methods of assuring relief from symptom, spiritual and psychosocial distress.

Palliative care is now typically defined as a philosophy applicable to care delivered to patients and family members from the day of a diagnosis of a serious, chronic or potentially life-altering disease or condition. With the aging of the population, this approach to care will become increasingly significant; while older people can live well with chronic disease, the health system will have to adapt to the new imperatives in care. These imperatives include a less sharp distinction between "well" and "dying" as even cancer now can be a chronic disease with a long time span, during which

“curative” and palliative care must coexist.ⁱⁱⁱ Care now is organized around a setting (home, hospital, nursing home) or a disease. With longer life expectancy, the aging of the population and variable insurance coverage, people will move back and forth between these sites and disease categories with greater frequency. This will require flexibility and adaptation to emerging needs. The concept of palliative care has benefits for all patients, including:

- Frail, elderly patients with non fatal chronic illness;
- Individuals facing life-altering chronic diseases such as MS, kidney disease, diabetes and other long-term diagnoses;
- Patients at home, in hospitals, nursing homes, assisted care settings and group homes.

Unfortunately, reimbursement for palliative care outside of hospice can become problematic and challenging. This concern, as well as the need for an increasing number of practitioners trained in this approach is a policy matter that must be addressed.

The research and advances in palliative care have accelerated rapidly in the past decade, although an energetic and robust research agenda remains a priority for the future. (See *Need for More Palliative Care Research*, page 5). Nonetheless, the components of palliative care can and should be integral standards of care for all patients and families as early as possible. Attention to palliation and quality of life can be the factors that permit continued compliance with a treatment protocol and can reduce the number of patients who reject recommended treatment options. Palliative care practices must incorporate and adapt to cultural and religious differences and beliefs. The essential concepts of palliative care are:

- A comprehensive team approach that incorporates flexibility and attention to quality of life relative to treatment options and outcomes;
- Full participation and control of patient and family in deciding who and what each member wishes to know and how they wish to participate;
- Application of new information about pain and symptom management, including attention to: nausea, fatigue, cognitive changes, gastrointestinal problems, eating, breathing and coughing, hypercalcemia, dyspnea, anorexia, depression and mood disorders;
- Planning for the anticipated, and unanticipated future needs including attention to needs and symptoms that may arise, retreat and reappear;
- Use of volunteers, integrative medicine and other approaches to ease suffering and reduce the burdens on patients and families.
- Incorporation of good communication skills and training for all participants in healthcare delivery.

It is clear that the hospice and palliative care are no longer synonymous; emerging principles of healthcare now incorporate the best practices of palliative care for all patients, from the point of diagnosis forward. While the hospice movement can be credited with the development of current palliative care concepts, they are a significant contribution to the advancement of healthcare for all people. Further research will be essential to adapt and advance these principles to all populations in healthcare.

References:

ⁱ Pan C, *Palliative Medicine*, WebMD Scientific American Medicine 2003, www.medscape.com

ⁱⁱ www.who.int/cancer/palliative care

ⁱⁱⁱ Lynn J, Adamson D. *Living Well at the End of Life*, Rand Health White Paper 2003 www.rand.org

The Role of Advanced Practice Nurses in Providing Palliative Care

by

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Palliative care is an approach to care that addresses the patient's physical, emotional, social and spiritual needs and seeks to improve quality of life not only for the ill person, but also for his or her family. Palliative care is best provided by interdisciplinary teams of professionals, often including physicians, nurses, social workers, chaplains or spiritual counselors, and other health care disciplines.¹

A primary tenet of palliative care is that clinical professionals be aware of and respect patient's treatment wishes. Although preferences vary according to race, ethnicity and religion, most Americans – more than 90 percent in a recent Gallup poll – want to be in their own homes or in a homelike setting when they die. Unfortunately, barely 20 percent of Americans die at home.

Other principles of palliative care, such as attention to physical comfort and personal dignity, pertain regardless of whether a dying person resides. Certainly, the 80 percent of Americans who die in institutions need and deserve expert

symptom management and attention to personal and interpersonal aspects of life closure.

Advanced practice nurses (APNs) can play a critical role in expanding access to services and improving quality of care for patients with advanced chronic illness including cancer. By facilitating coordination and maximizing continuity of care, APNs are not only particularly helpful to patients and families, but also highly valued by their clinical colleagues and administrators.

The advanced practice registered nurse has a master's or doctoral degree and has concentrated in a specific area of advanced practice nursing. She or he has had supervised clinical training in a specific area of practice at the graduate level as well as ongoing clinical experience. Palliative care advanced practice nurses often can provide patient care and family support through the continuum of care and disease trajectory. Practice as members of interdisciplinary teams, APNs work with patients and families: They use listening skills to learn the full spectrum of patient and family concerns and to serve as patient/family advocates. Working closely with physicians on the palliative care team, APNs contribute to diagnostic evaluation and treatment.

In addition to direct involvement with patients, APNs in palliative care act in a variety of other roles. They can be designers of innovative practices for end-of-life care in a variety of settings. As educators of and consultants to other clinicians, medical residents, nursing students and other providers, they model and mentor effective modes of caring. APNs also serve as researchers who make important contributions to the professional literature and body of knowledge. As administrators within health care systems, institutions and clinical education programs, APNs manage the delivery of valuable health care services at the point of patient contact. Working with institutions and communities, APNs reach those in need while

managing resources in an efficient, cost-effective fashion.

In 1998, NYU was the first program in the country to offer a master's degree or post-master's certificate to prepare nurse practitioner to provide comprehensive and compassionate care to individuals and families who are living with or dying from an incurable, progressive illness. A number of graduate programs now offer advanced education in palliative care nursing.

Advanced practice nursing in palliative care offers an exciting career opportunity that can help attract a new generation of men and women to the field of nursing and the proud profession of caring. Currently, however, APNs face challenges in training and licensure, and they may encounter regulatory and reimbursement barriers. With the development of generalist and advanced practice credentialing examinations and the creating of advanced practice programs in palliative care nursing, the time has come for palliative care nursing to be recognized as a specialty in all states. With this recognition, the dream of making effective and compassionate care available for seriously ill and dying patients and families will be one-step closer to becoming a reality.

Reference:

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Need for More Palliative Care Research

by

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It is essential for health care providers to determine the best approaches for meeting the psychosocial care needs for persons with a progressive illness as well as their family and those close to them.

In order to determine best practice guidelines on the most effective models of care there is a need for more research evidence. There are, however, a number of difficulties in generating and applying evidence-based approaches to palliative care.

Researchers often face a number of problems conducting studies on palliative care. Although the randomized controlled trial (RCT) remains the gold standard to determine the efficacy of treatments, some palliative care cannot be easily investigated by a traditional RCT. Rinck et al¹ examined 11 randomized-controlled trials: all had methodological problems. Problems were associated with recruitment of a study population in 10 studies, homogeneity in six, patient attrition in four, defining and maintaining contrast between interventions in six, and selecting outcome variables in four. In two studies, the problems were so severe that no results were reported.

Hearn & Higginson² evaluated 18 prospective comparative studies, retrospective and observational studies as well as randomized trials. When specialist multidisciplinary care was compared with conventional care, four of the five randomized controlled trials and most of the comparative studies indicated that the specialist,

coordinated approach resulted in similar or improved outcomes in terms of patient satisfaction; patients being cared for in the place of their choice; family satisfaction; and control of family anxiety, patient pain, and symptoms. Those studies that examined costs showed a reduction in hospital inpatient days, more time spent at home, and equal or lower costs.

The findings of a systematic review of 384 published studies³ reported that both the characteristics of subjects and methods used are disparate, and that much of the research has been preoccupied with describing activities and problems in palliative care rather than actively evaluating existing and new approaches to care and health outcomes.

Psychosocial outcomes such quality of life are hard to measure, especially when patients are frail and ill. Thus, many studies exclude quality of life as an outcome variable, or include only patients who can complete questionnaires. The challenge is to ensure that those aspects of care that are hard to measure do not become a lower priority than outcomes that are easier to measure such as survival or functional status.

Problems continue to exist in measuring quality of life among patients with a progressive illness. In reviewing different models of palliative care, Salisbury et al⁴ concluded that although inpatient hospice care resulted in better pain control than conventional care other aspects of quality of life were inadequately measured and the evidence for hospital and home palliative care teams very limited.

Symptom management in palliative care is an area in need of continued research. Donnelly, Walsh, & Rybicki⁵ reported the first prospective, systematic analysis of the severity of 37 symptoms in 1000 patients with advanced cancer. Pain,

fatigue, and anorexia were consistently among the 10 most prevalent symptoms associated with cancer at all sites. When pain, anorexia, weakness, anxiety, lack of energy, fatigue, early satiety, constipation, and dyspnea were present 60%-80% of patients rated them as moderate or severe in terms of clinical importance. The most common symptoms were also the most severe. Clinically important dyspnea, hoarseness, hiccup, and dysphasia were more common in men; anxiety, nausea, vomiting, and early satiety in women.

In addition to physical symptoms, psychological symptoms are commonly experienced by patients with advanced cancer. More than one third of dying patients may be depressed, and more than one-half of patients with advanced cancer feel sad, anxious, and irritable⁶. Research suggests there is still much mismanagement regarding patients' psychological distress. Oncologists themselves recognize that they are not nearly as competent in addressing the psychological symptoms of the dying as they are in addressing pain and other physical symptoms. The 1998 survey of ASCO members reported revealed that although more than 90% of oncologists felt competent to manage nausea, vomiting and pain, only 50% felt similarly competent to manage depression. There is a general uneasiness about psychological distress and discussing end-of-life issues with patients⁷.

There is also a need for research on families/care givers of palliative care patients. Research should focus on projects that justify the role of palliative care team working with family members and show which interventions are most effective in improving the psychosocial and spiritual wellbeing of patients and families during the palliative care journey.

Clearly difficulties remain in the rigorous gathering of evidence about many aspects of palliative care. However, these difficulties should

not be allowed to stand in the way of applying palliative care where its efficacy, patient and family satisfaction, and cost-effectiveness have been shown. The priorities are to determine best practices, to develop standards that will apply to all services, and to evaluate those aspects of palliative care, which remain unevaluated.

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